

Piloting the draft accessible information standard

1 Scope and scale of the pilot

The Clatterbridge Cancer Centre is one of the largest networked cancer centres in the UK. Combining its world-class clinical services, research and academic excellence, the Centre provides the highest quality, specialist nonsurgical oncology treatment and care for more than 2.3million residents in Merseyside, Cheshire, North Wales and the Isle of Man as well as national and international cancer patients. We treat in excess of 27,000 patients per year, registering 8,000 new patients each year and providing more than 130,000 attendances for treatment.

The Pilot site for the draft accessible information standard was the whole organisation excluding The Clatterbridge Clinic (our private patient unit).

The Clinical Specialist for Additional Needs, Macmillan Information and Support Managers and the Patient Services Team documented all requests for accessible information during the pilot.

During the pilot phase (31/01/2015 – 31/03/2015) our Clinical Specialist for Additional Needs made contact with 31 patients known to have information and / or communication needs, this contact was on the initial visit where the patients were reviewed, along with their carers where appropriate. All information was discussed at a level that was deemed appropriate for the individual and in 3 cases the information about Radiotherapy was given in an 'easy read format', with a carers guide to accompany it. Both documents are readily available from our Macmillan Information Centres.

2 of the patients were blind/partially sighted and required information to be put on a CD by the local Society for the Blind and Partially Sighted – the turnaround for which was approximately 4 days.

All records were adjusted to include details of the individuals' information and / or communication needs in line with the Trust Policy. For each patient a Reasonable

Adjustment Plan was completed, a 'blue dot' sticker was applied to the Patients case notes/ patient folder and an annotation regarding the communication needs documented.

The Macmillan Information and Support Managers and the Patient Services Team did not receive any additional requests for accessible information during the pilot phase.

2 Actions taken to effectively implement the standard into existing systems

2.1 Systems used to implement the standard

A paper-based system to identify, flag and record if a patient/ service user has communication or information needs relating to a disability, impairment or sensory loss was implemented immediately prior to the pilot phase and is documented in the Trust policy 'Use of Additional Needs Alert Sticker' policy. The policy was launched 19/01/2015 and additional training for Medical Records (Non-clinical) staff commenced 26/01/2015.



Use of Additional
Needs Alert Stickers \

2.2 How the standard was implemented

Our Clinical Specialist for Additional Needs provided face to face training with key clinical and non-clinical staff on the use of the additional needs alert stickers. Further training took place during the pilot phase and has continued.

An email was sent by the Clinical Specialist for Additional Needs to all heads of departments and Medical staff informing them of the pilot. The pilot was also advertised to all Trust staff via the Trust e-Bulletin 22/01/2015.

2.3 Changes to policies and procedures

During the pilot we investigated the possibility of introducing electronic flags and this work is still on going. The Trust plans to introduce a new Electronic Patient Record system early next year (February 2016) and this will allow us to flag patients with communication or information needs relating to a disability, impairment or sensory loss. It is still unknown if the new system will allow us to provide correspondence in alternative formats automatically.

A draft Accessible Communication Policy has been compiled based on the ISB 1605 Accessible Information Standard Specification draft. Once the specification draft has been finalised the Trust policy will be updated accordingly, document controlled in line with Trust policy and made available to all Trust Staff. A programme of training will also accompany the introduction of this policy; this will include training all patient facing staff to ask all patients/ service users (and where appropriate their carers and parents) if they have any information/communication needs.

During the pilot it was decided that an annotation should be included in Aria, the electronic system that holds the radiotherapy treatment plan, for patients with an alert sticker. The memo (inserted below) was circulated to all relevant staff and guidance will be included in the 'Accessible Communication Policy'.



Aria memo
1022015.docx

As a Trust we are confident that once a patient/ service user is identified as having communication or information needs relating to a disability, impairment or sensory loss we are thorough in our approach and are able to provide appropriate information and communication support. We are now working on ways to ensure that all patients with communication or information needs are identified and flagged in advance of their treatment commencing. As a result we have updated our policy 'The management of patients attending with additional needs' which now includes an Audit section (draft policy attached). We are looking to convert the 'Use of Additional Needs Alert Stickers policy to a procedure

document and change its title to 'Alert Stickers' as this document is not limited to patients with additional needs.



Management of
Patients Attending W

Our Trust Wide Guideline 'Communication Support Guidance: accessing and using interpreters, translation services, assistance and facilities' is also currently under review following the pilot project. Additions to this document will include guidance on staff responsibilities to ensure that all patients/ service users requiring 'personal' or 'direct' communication (for example correspondence in an alternative format) and 'generic' / 'indirect' communication (for example leaflets or manuals) do not receive standard print documents and, guidance for staff on how to 'call' patients with communication or information needs through for appointments.

3 Impact and cost of implementing and following the standard

The Trust utilised the funding provided as part of the pilot study to fund the Clinical Governance Manager for Patient Safety to dedicate 60 hours of her time to reviewing the pilot documentation, updating and creating Trust policies in order to fulfil the requirements of the Standard and to investigate IT options to convert the paper-based system into an electronic system.

During the pilot we investigated the use of text phones for patients/service users with information/communication needs and these have now been ordered using funding provided as part of the pilot study.

The impact on staff has been minimal due to the small numbers of patients identified during the pilot phase as having communication or information needs relating to a disability, impairment or sensory loss.

Patients whose first language is not English and therefore require translators and written information translated have a much more significant staff time and financial impact on the Trust, however they are excluded from the scope of the standard.

Staff training for supporting and caring for patients with additional needs is already embedded within the Trust and is part of our 'business as usual'. We currently offer mandatory communication skills, safeguarding and equality & diversity training, dementia awareness training, caring for patients and service users with Learning disabilities training and Deaf awareness training. We are looking to expand the scope of our training over the coming months.

The Written Information Group has expanded its scope to review the content of the correspondence letters we send to our patients. The group has agreed the following paragraph to be included in all future letters to our patients.

"CCC letters and information can be made available in a range of formats on request (e.g. Audio, large print, easy read, Braille, BSL or other languages). Please contact Patient services on patient.admin@clatterbridgecc.nhs.uk or telephone CCC x 5157 if you require this service."

4 Feedback on the practicality of implementing the standard using existing documents/ in its current form

The comprehensive array of documents that accompany the standard, whilst helpful, did provide a barrier to the implementation of the standard due to the time required to read the documents and translate them into practice.

We were in the fortunate position that prior to committing to pilot the standard we had already investigated within the Trust a paper-based system to flag patients with Additional Needs, and were therefore able to implement this with minimal disruption to staff.

The Standard states that 'Paper-based systems and documentation MUST enable recording of needs in line with the human readable definitions of the data items associated with the subsets defined by the standard.' This was not possible for the Trust to implement during the

pilot phase as the staff involved in the project did not have experience of using these codes and found it difficult to identify expertise in the Trust in such a short timeframe. More guidance on what is required with regards to the recording of needs in line with the human readable definitions of the data items for Trusts implementing a Paper only based system would be valuable.

5 Feedback on the usefulness of the Implementation Guidance in supporting implementation of the standard

Currently, our Trust process is to refer patients/ service users with any additional needs to the Clinical Specialist for Additional Needs who discusses those needs with the patient/ service user (and where appropriate their carers and parents) and puts a plan in place to ensure those needs are met. We hope to expand the knowledge of our patient facing staff to give them the resources and confidence (especially for those who are non-clinical) to accurately ascertain and record patients/service users information and communication needs directly, as some of the patient needs could be solely accommodated by the staff member asking about the needs (i.e. receptionist/secretary) without referral to the Clinical Specialist for Additional Needs. The scenario examples in the Implementation Guidance are very helpful and staff would value more examples if available.

6 Assessment of the effectiveness and clarity of the Specification, Implementation Plan and Clinical Safety Case

The Standard Specification draft is a comprehensive document. It would, however, benefit from being more concise, if possible.

The specification draft refers to SNOMED –CT and Read Codes however it expects the reader to have knowledge of these. It would be helpful to provide a lay description for those readers who have no prior knowledge.

With regards to the Clinical Safety Case, we did not identify any issues with Hazards 1 and 2 during the pilot that have not already been raised above, however it would be helpful if some guidance could be provided to help Trusts identify those that fall under Hazard 3.

To minimise Hazard 3 we plan to conduct a once yearly audit of a random sample of patient records (*those patients who have attended the Trust within the previous 12 months*) to assess the following:

- a) If patient flagged as having communication or information needs relating to a disability, impairment or sensory loss, have those needs been appropriately met? Have they been recorded accurately?
- b) If patient has not been flagged, does the patient have any communication or information needs relating to a disability, impairment or sensory loss? i.e. have we failed to identify and/or flag their needs.

7 Benefits / efficiency savings associated with implementing / following the standard

- ‘Did Not Attends’ (DNAs) - We were unable to measure any increase or decrease in DNAs during the pilot period.

- Clinical scheduling: implementation of the standard did not have an impact on clinics/ sessions running on time.
- Complaints and the patient/ service user experience: the patients for whom accessible information was provided reported that they were happy with the information provided. No complaints were received regarding information and communication support during the pilot period.

8 Any other Comments

The Trust would like to thank NHS England for the opportunity to participate in the pilot of the accessible information standard. We have made process changes that will benefit our patients and we are looking forward to making further improvements to our processes to ensure that our patients' information and communication support needs are continually met.

It would be helpful to have a leaflet, produced by NHS England, in a variety of formats (easy read, braille, audio etc.), that describes the accessible information standard for patient/ service users, which encourages them to request information in alternative formats if required, asks for their feedback (questionnaire?) if alternative formats are provided and also tells them how they can raise comments, concerns or complaints within the providing organisation. In addition, it would also be helpful if NHS England could provide poster templates for Trusts to advertise their commitment to the standard and the services available.

At the 'Effective implementation of the accessible information standard' workshop in Leeds 27/03/2015, a patient representative mentioned a 'prescription' sheet which asked the patient/service user or their carer to 'tick' the relevant boxes for how they would like to receive information/ communicate with the Trust i.e. email, BSL interpreter. Could this be combined with the SNOMED –CT codes list for staff to record the requirements?